

Quality of Life Outcomes for People with Alzheimer's Disease and Related Dementia

Care Planning Tool for Providers

Outcomes, Indicators, Measures & Related Good Practice



Developed by:
Wisconsin Statewide Advisory Committee on
Quality of Life Outcomes for People with Alzheimer's Disease and Related Dementia

Sponsored by:
Wisconsin Department of Health and Family Services
Division of Elder and Disability Services
Bureau of Aging and Long Term Care Resources, and a
Federal Administration on Aging Alzheimer's Disease Demonstration Grant

Document Number PDE-3195

This project was supported, in part, by a grant, number 02-90AZ236901, from the Administration on Aging, Department of Health and Human Services, Washington D.C. 20201.

Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.

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Introduction to the Dementia Outcomes Care Planning Tool

As part of the State of Wisconsin's initiative to improve services for people with dementia in the community based long term care system, an advisory committee was formed to define quality of life outcomes important to people with dementia. The committee was comprised of 23 experts representing each service field of dementia care, demographic, and region of the state, and included two dementia family caregivers and a consumer in the early stages of Alzheimer's disease.

The ***Dementia Quality of Life Outcomes Care Planning Tool for Providers*** is the result of the committee's two years of work to develop a tool that would guide providers to plan ways of supporting the best quality of life possible for people suffering from Alzheimer's disease and related dementia. It is the intent of this guide to help people plan for things in specific ways that acknowledge needs that may not be able to be voiced, as the disease of Alzheimer's progresses.

There are many ways of looking at quality of care issues for people with Alzheimer's disease and related dementia. However, this guide seeks to go beyond "care" to recognize how "quality of life" can be recognized, nurtured and celebrated. In this process care providers and recipients become partners on a journey of discovery, interdependence and respect.

The advisory committee chose to state all of the outcomes and indicators in the first person, as the voice of the person with dementia stating what she or he wants and needs. Pilot studies with this tool proved that, when this language was used, it was powerful in helping caregivers look at the person with dementia in very personal ways that brought them together in a growing and learning experience. Care providers came to know the people in their care and were excited about ways they could enhance quality of life that impacted them both.

This guide seeks to encourage those who use it to become the keepers of the life story and personhood of the person with dementia, and to seek to provide ways of preserving continuity in the future as the disease progresses.

The advisory committee that conceived of this guide spent two years envisioning what quality of life for people with Alzheimer's disease meant, and refining that vision into what they hoped would be a practical tool for others to recognize and support these elements and experiences. Although the guide has been tested on a preliminary scale, it remains a work in progress, in that it will continue to be improved as people continue to use it over time.

Introduction (Continued)

Please see the appendix for:

- The procedure for using this tool
- The accompanying documenting form
- The Project Description describing the advisory committee, how the tool was developed and the experience of pilot sites.

Questions and comments about this project or the use of the ***Dementia Quality of Life Outcomes Care Planning Tool for Providers*** may be directed to:

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Please see the Wisconsin Department of Health and Family Services web site for additional information, materials and resources on dementia care, and a current electronic version of this tool at:

<http://dhfs.wisconsin.gov/aging/genage/alzfcgsp.htm>

Overview - Dementia Outcomes Care Planning Tool

The Dementia Outcomes Planning Tool has been developed to provide a structured approach to examining and planning for quality of life issues with people who have dementia. The guiding principles and specific information allow care providers, in collaboration with care managers and consumers, to personalize and focus planning and monitoring of care for persons with Alzheimer's disease and related dementia. Although these guidelines are general, it is expected that they be used to identify specific things that are important to the individual that can be followed, monitored and measured over time in order to insure that the person's quality of life is fully supported.

This Tool Recognizes Certain Values in Dementia Care:

1. **Consumer-focused:** People are given choices and assistance to live their lives as they please. Each outcome, related indicators and measures can be individualized for each person's unique lifestyle and preferences.
2. **Disease progression:** In recognizing the progressive nature of Alzheimer's disease and related types of dementia, the outcomes and indicators stated here relate broadly to all persons with dementia. However, depending on the stage of disease progression, there may be differences in how the outcomes are achieved and measured.

The tool follows this general approach to defining the indicators, measures and best practices for each outcome:

- a. In the early stages of the disease, people with dementia should be supported so that they **can maintain** the lifestyle, practices, and choices that they had prior to having the disease to the fullest extent possible. Many measures in the early stages are obtained from self-report.
- b. In the intermediate stages, the indicators, measures and good practices reflect the fact that the person **is assisted** so that s/he is able to maintain preferred lifestyles as much as possible. The person is given opportunities to do things with assistance and accommodation. Many measures are obtained from observation, some self-report and some in interviews with the person and caregivers. It is also important to have physical measures as evidence. At this stage, it is not reliable to only question the person, although it is still important to do so to the extent possible.
- c. Finally, in later stages, the indicators, measures, and good practices **honor previous choices** that characterized the person's life prior to significant disease progression. Most measures are obtained through physical measures, direct observation and assessments, and from caregivers. In later stages, caregivers need to be providing care for the person in a way that acknowledges the person's past and continues her or his preferences.

Definition of Terms

- **Outcomes:** these are broad statements – or guiding principles – that identify necessary quality of life elements from the person with dementia’s perspective. The outcome statements are deliberately authored in the first person to give them the power of being stated by the consumer with dementia.
- **Indicators:** are the more focused statements that describe a particular aspect of the broader outcome. The indicators define specifically how the outcome will be present. In most cases, the indicators are applicable to all people with dementia. (There may be different indicators used for different disciplines, e.g. nursing and medically related indicators vs. activity program and psychosocial indicators. Not all indicators will apply in certain settings, or to all people, depending on personal preferences and stages of dementia they are in.)
- **Observable Measures:** are the measurable information gathered from various sources to determine the presence of the indicator. Suggested measures were chosen to reflect things that are important to 50% or more of people with dementia, but are not all-inclusive. The measure should answer the question, *“What specific information can be found that shows the indicator is present?”*

Each measure should be information gathered from:

- a person with dementia, or one who knows the person well, reporting something in an interview
- a measurement tool or test
- an observation of a person’s behavior, interactions, setting, etc.
- an assessment
- other data from records, etc.

The information gathered must be tangible and specific data. Each measure should include the source for the information (caregiver, person with dementia, file records, staff, etc.) However, the most reliable source is not necessarily a physician; it may be a caregiver or family member.

- **Good Practices:** are the actions that care providers could ideally be taking to produce the conditions for these outcomes to be met. The good practices identified are meant to provide a context for the indicators and measures chosen, and are not meant to be all-inclusive. They are suggestions taken from practices in the dementia field, and may not necessarily be appropriate for all consumers or in all care settings.





QUALITY OF LIFE OUTCOMES FOR PEOPLE WITH DEMENTIA

OUTCOMES:

As a person with dementia,

I have the best possible physical well-being

I have meaningful relationships

I experience hope because my future is valued and supported

I am accepted and understood as an individual

I am involved in life

“As an individual with dementia, I value some of these outcomes more than others, depending on my personal preferences. Also, my priorities are different from others who have dementia, and this is honored by my care providers.”



Related Outcome – Regarding Caregivers:

As a person with dementia,

I have caregivers who are educated and supported

(Note: details of the caregiver outcomes are covered in another document, and are not incorporated into this tool)

Outcomes and Indicators:

1. As a person with dementia, I have the best possible physical well being

I am well hydrated
I am well nourished
I am comfortable – free from pain
I am physically active
I am clean
I am safe
My medical needs are being treated by people knowledgeable in dementia
I receive the least restrictive intervention for my behavior symptoms

2. As a person with dementia, I have meaningful relationships

I am supported in maintaining ongoing relationships as desired and
I am provided with opportunities to develop new relationships as desired
With:
- Family
- Friends and Peers
- Formal Caregivers
- Pets
- Other Generations
I have the opportunity to maintain an intimate* relationship with my spouse/partner as desired within my capacity (**intimate = physically and emotionally close, sexual as person's competency/consent allows*)

3. As a person with dementia, I have hope because my future is valued and supported

I participate to my capacity in all decisions effecting my life
I am useful and make contributions of value
I plan and do things I've wanted to do while I still can
I have the emotional support and encouragement that I need
I have positive things to look forward to and do
I have a legally supported plan for my future needs and wishes
My previous wishes are honored as my capacity diminishes
I continue practices that nourish me spiritually

Outcomes and Indicators (Continued):

4. As a person with dementia, I am accepted and understood as an individual

I am treated as a person not a disease, and am acknowledged as “present”
I am cared for by people who understand me, and about my dementia
I have regular opportunities to access and share my rich & meaningful past
I practice rituals that comfort or calm me
I continue my own cultural lifestyle
My orientation to time and reality is respected and supported
I continue my familiar routines
My environment is anchored in things I value that are familiar to me
I have continuity in relationships with caregivers
I have physical privacy
My sexual identity is treated with respect
I am free from all forms of abuse

5. As a person with dementia, I am involved in life

I engage in activities that are meaningful to me daily
I have the opportunity to participate in the life of my community
I am able to communicate with others to my highest capacity
I am able to do things independently with safe supports
I enjoy the tastes, smells, sounds, and feelings of the real world
I have the opportunity to enjoy/be outdoors



The next section contains the care planning segments of this guide. Each individual outcome is listed separately with its indicators, followed by the area that covers suggested measures and related good practices for each indicator.



Outcomes and Indicators:

Outcome Number One

As a person with dementia, I have the best possible physical well being

1. I am well hydrated
2. I am well nourished
3. I am comfortable – free from pain
4. I am physically active
5. I am clean
6. I am safe
7. My medical needs are being treated by people knowledgeable in dementia
8. I receive the least restrictive intervention for my behavior symptoms



OUTCOME ONE: I have the best possible physical well-being

Indicator 1: I am well hydrated

Observable Measures:	Related Good Practice by Caregivers:
<u>Physical Measures</u> <ul style="list-style-type: none"> Physical tests of hydration (e.g., urine concentration, skin turgor, etc.) 	<ul style="list-style-type: none"> Periodic monitoring of hydration is done when dehydration is a concern, e.g.: daily weight taken, urine concentration dip-stick test, skin turgor, fluid input/output measures, etc. Person and/or caregiver(s) recognize symptoms of dehydration and how to address them, including the importance of knowing when a medical emergency may be present and under which circumstances seeking medical help is indicated
<u>Observation</u> <ul style="list-style-type: none"> A variety of fluids and fluid containing products present in home or person's quarters Person observed being given and drinking fluids 	<ul style="list-style-type: none"> A variety of fluids (or fluid containing items e.g., frozen juice, Popsicle's, soup, nutrition shakes, etc.) which the person likes, are available and given to the person in an established fluid routine throughout the day – especially in the early afternoon to minimize "sundowning" agitation symptoms (all fluids count)
<u>Records</u> <ul style="list-style-type: none"> Measures of routine fluid intake and output Daily weight checks Results of physical tests 	<ul style="list-style-type: none"> Person, and/or caregiver(s) understand the consequences of dehydration in exacerbating the person's <u>specific</u> concurrent health conditions, dementia symptoms, and possible experiences with dehydration in the past
<u>Interview</u> <ul style="list-style-type: none"> Person and/or caregiver report routine of fluid intake, types, frequency & likes Person/caregiver(s) demonstrate understanding of how much fluid person needs and how often, to maintain good hydration 	<ul style="list-style-type: none"> Person, and/or caregiver(s) understand the importance of good hydration in avoiding health risks (such as increased confusion/cognitive problems, illness, urinary tract infections, incontinence, complications of diabetes and other chronic conditions, etc.)

Indicator 2: I am well nourished

Observable Measures:	Related Good Practice by Caregivers:
<u>Physical Measures</u> <ul style="list-style-type: none"> Body weight Blood tests for vitamin and/or nutritional deficiencies Person chewing and swallowing appropriately 	<ul style="list-style-type: none"> Caregivers are educated on importance of monitoring person's nutrition and how nutritional issues can influence that person's dementia symptoms and concurrent health conditions (e.g., diabetes, stroke risks, digestive disorders, etc.)

OUTCOME ONE: I have the best possible physical well-being

Indicator 2: I am well nourished *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person observed eating a balanced meal – appears to enjoy food • Menu posted/available • Variety of nutritious foods on hand – easily available to person • Methods reported to be in use for maintaining nutrition are observed (e.g. person eating with someone, being fed appropriately, finishing food on plate, adaptive aids used, etc.) • Dates on food indicate still edible, food stored properly • Dentures are used during eating without discomfort 	<ul style="list-style-type: none"> • Methods are in place to help the person with dementia maintain regular nutritional intake and healthy body weight. (Examples: help with shopping and/or cooking, home delivered meals, regular home checks and weight checks, regular arrangements for others to eat meals with the person, caregiver education on person's nutritional needs and how to meet them, etc.) • A plan is in place to verify that the person receives and eats 3 meals per day (covering the gaps when home delivered meals are not delivered, assuring that all meals are being eaten) • Frozen meals are on hand to serve as back up for home delivered meals on weekends, holidays or times when person dislikes the food that is delivered • Food safety monitored - periodically checked for expiration dates, discarded if spoiled, etc.
<p><u>Records</u></p> <ul style="list-style-type: none"> • Dietary log indicates regular, balanced food intake • Menu of meals, notations on food eaten/left at each meal • Results of OT evaluations, nutrition consultation, swallow studies, etc. • Records of routine supplements taken 	<ul style="list-style-type: none"> • If person has problems with chewing, eating or maintaining body weight, (e.g., pacing constantly, won't sit and eat, can't use utensils, problems swallowing, etc.) occupational therapy, dental and/or nutritionist evaluation is done to obtain adaptive equipment, environment arrangements, dental and/or nutritional strategies • If person is suspected of having problems swallowing or may possibly be inhaling food, a referral is made to an Occupational Therapist to conduct a swallow study
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Person reports feeling full or satisfied after eating • Person and or caregiver identify food person enjoys, eats routinely • People doing periodic home checks report variety of foods on hand, absence of spoiled food, evidence that food is being eaten • Person and or caregiver identify use of adaptive aids, supplements, measures to encourage eating, etc. 	<ul style="list-style-type: none"> • Regular monitoring of eating habits by another competent person is done (e.g., neighbor, relative, care provider who reports back with observations made at person's home, etc.) • Non-perishable food left out and visible to person, prompts person to eat • Smaller, more frequent meals, use of small plates, meal replacements (e.g., Ensure), etc. are offered if person is unable to eat much in one sitting, or expends a great deal of energy during day – leading to problems maintaining weight • If person refuses food at mealtime, it is offered again at ½ hour time intervals

OUTCOME ONE: I have the best possible physical well-being

Indicator 3: I am comfortable – free from pain

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Physical Measures</u></p> <ul style="list-style-type: none"> • Person's range of motion, tolerance for routine positions, movement weight bearing and mobility • Skin warmth, swelling, damage, etc. in effected area 	<ul style="list-style-type: none"> • Routine assessment for pain symptoms done whenever there is a change in the person with dementia's behavior, agitation level, usual participation, activities, etc. • Physician knowledgeable about chronic pain intervention is involved in person's treatment
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person is active - appears to be able to move freely through environment and perform routine tasks comfortably or with minimum of discomfort • Person able to sleep comfortably • Person has body relaxation – absence of tensing, limping or favoring • Systematic, ongoing observation of person's actions assesses for possible pain (e.g. resisting care, restlessness, agitation, facial expression, limited movement, yelling or calling out, etc.) • Comparison of noticeable symptoms prior to and after administering pain reliever 	<ul style="list-style-type: none"> • Note: the Assessment of Discomfort in Dementia (ADD) Protocol is used in settings where ongoing nursing support is in place • Person's health history is reviewed for possible conditions that could cause current or future pain (e.g., old injuries, chronic or reoccurring illness, arthritis, etc.) • Behavior is monitored for possible pain symptoms through regular physical assessment/observation • Non-pharmacological "comfort" approaches used to try to relieve or diminish pain (e.g., positioning, massage, relaxation, exercise/stretching, etc.)
<p><u>Records</u></p> <ul style="list-style-type: none"> • Health history indicates conditions that could potentially result in chronic or episodic pain are identified and assessed • Pain management plan is in place • Medication log indicates pain medications routinely given & adjusted • Records indicate results of routine assessments and person's response to interventions 	<ul style="list-style-type: none"> • Trial of physician approved pain reliever (e.g., acetaminophen) is tried to assess effects on symptoms when non-pharmacological approaches do not seem adequate • A pain management plan – including regular assessment and routine administration of scheduled pain medication – is followed (person is not expected to request medication in order to receive it)
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Person is able to focus on conversation, activities etc., without referring to discomfort • Caregiver able to identify person's non-verbal signals that s/he is in pain, reports examples of decrease when pain relief measures taken 	<ul style="list-style-type: none"> • Communication about person's symptoms and approaches used to relieve them are communicated to all caregivers routinely in order to maintain continuity of person's pain management

OUTCOME ONE: I have the best possible physical well-being

Indicator 4: I am physically active

Observable Measures:	Related Good Practice by Caregivers:
<u>Physical Measures</u> <ul style="list-style-type: none"> Strength, stamina and balance testing and/or assessment Person demonstrates range of motion, physical strength, stamina and physical abilities at a consistent level 	<ul style="list-style-type: none"> Person is encouraged to walk, use body and abilities as much as possible – opportunities are built into daily routine Person does strength training as recommended and able, to maintain optimal health and balance ability
<u>Observation</u> <ul style="list-style-type: none"> Person able to participate in routine physical activity easily Person able to participate in their daily exercise plan/activities to their capacity 	<ul style="list-style-type: none"> Adaptive equipment is in good repair and used consistently (e.g., walkers, canes, etc.) Shoes/footwear are sturdy, in good condition, fit comfortably and are worn consistently Person participates in regular exercise that s/he enjoys, and is appropriate for maintaining person's maximum function and concurrent health conditions (e.g., osteoporosis, arthritis, etc.), even if only simple range of motion activities when bed-bound
<u>Records</u> <ul style="list-style-type: none"> Documentation of activity and participation Documentation of assessments of person's physical ability levels over time Fall prevention/home safety evaluation 	<ul style="list-style-type: none"> Person and environment are assessed by occupational therapist and recommendations are implemented, to minimize person's possibilities for falling Rehabilitation and/or recovery opportunities are attempted when person has setbacks due to illness, injury, etc.
<u>Interview</u> <ul style="list-style-type: none"> Person and/or caregiver report ability to participate in exercise and daily routine activities 	<ul style="list-style-type: none"> Caregivers are educated on ways to breakdown tasks, offering minimal assistance, and allowing person to continue to do as much as possible on their own, to avoid excess disability Person is physically supported to continue using body and skills (e.g., eating at the table, assists with transferring, walks wherever possible, participates in household routines)

Indicator 5: I am clean

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Person has absence of odors and/or is pleasant smelling 	<ul style="list-style-type: none"> Person participates/assists in own care as much as able and encouraged to maintain own cleanliness habits

OUTCOME ONE: I have the best possible physical well-being

Indicator 5: I am clean *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u> <i>(continued)</i></p> <ul style="list-style-type: none"> • Grooming of hair, beard, face, skin, nails, etc. evident • Clothing is clean in appearance • Teeth, dentures and gums are clean, free of odor, decay, disease, etc. • Dentures are used during eating and rinsed/cleaned afterwards, cleaned thoroughly at night 	<ul style="list-style-type: none"> • Person's past routines/preferences respected and documented, incorporated into routine care (e.g., prefers bathing 3X per week, hair washed at salon, etc.) and shared with all caregivers • <u>Techniques to minimize resistance to bathing:</u> <ul style="list-style-type: none"> - Engage person in the activity - offering them a washcloth, shampoo, etc. - Create sensory environment – lowered lighting, music, aroma therapy, water toys, even food - Cover parts of person not being washed with a soft warm towel or blanket for modesty, warmth - <u>Invite</u> the person to bathe – treating it as their special time to be pampered - Offer bed baths as alternatives, use products that don't require bathing or wetting the whole person, etc. - Try bathing at different times according to person's good/more difficult times of day (e.g., before bed to soothe and relax, after lunch prior to nap, to ease pain ½ hour after medication administration, etc.) - Investigate person's past bathing habits when younger, duplicate rituals/habits from then
<p><u>Records</u></p> <ul style="list-style-type: none"> • Routine dental, hair, nail, bathing, etc. care is documented • Person's preferences, refusals, techniques tried for engaging in participation and successful strategies for overcoming resistance are documented for all caregivers to reference 	<ul style="list-style-type: none"> • Duplicates of favorite clothes that person wants to wear continuously are purchased to allow for washing • Person's clothing is spot-checked for stored food if person tends to pocket/save food items from meals • Hair, skin, facial hair and teeth are groomed daily or as needed (e.g., after naps) • Clean clothes are put on daily or changed when soiled • Regular oral/dental care with dentist done every 6 months, more frequently if needed – teeth and/or dentures repaired when broken or lost
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Person/caregiver(s) able to identify ways person participates in care, preferences, etc. • Family or people routinely with person can attest to regular cleanliness 	<ul style="list-style-type: none"> • Caregivers are introduced to the person with dementia, build rapport and a relationship of trust before helping person with personal care activities • Maintain continuity - the same caregiver does all of the person's bathing to preserve trust

OUTCOME ONE: I have the best possible physical well-being

Indicator 6: I am safe

Observable Measures:

Observation

- Person moves through/uses environment confidently
- Adequate locks etc. on doors
- Safeguards and adaptations are in place that address the person with dementia's behavior symptoms, increases safety and assists in maintaining skills

Related Good Practice by Caregivers:

General Guidelines:

- Safety - Lighting, non-glare evenly colored floors, clear pathways, corridor and stairwell railings, bathroom equipment, modified appliances, safe water temps, no throw rugs, poisonous items secured in locked area, car not easily accessible, adequate amount of monitoring by others, etc.
- Wandering deterrents – motion detection warning alarms, door alarms, disguised doors, dark removable floor mats, registry with safe-return program, safe places indoors and out to pace/walk off energy, etc.
- Wayfinding aids– pictures/words on cabinets, drawers, closets, bathrooms identifying contents; calendar, clock, etc.
- Homelike/familiar setting - person's room is filled with familiar objects, photos, reminiscent items, arrangement similar to previous home, room easily identified from doorway, etc.
- Privacy/security – adequate security of belongings, personal space is respected, area where person can go to be alone/away from noise/have private time, etc.

Records

- Evidence of a dementia specific home-safety evaluation, written recommendations and their implementation
- Evidence of appropriate levels of routine monitoring and supervision – including natural supports
- Incident reports of preventable injuries, issues (wandering/driving) indicate an alternate plan is in place and being followed to prevent further issues.
- Baseline screening done for trauma, abuse – followed up where appropriate
- Documentation of complaints, resolutions (or lack of complaints)

- Occupational therapist conducts home safety and adaptive aid evaluation, makes recommendations for changes that may enhance person's ability to live at home
- Assisted living facilities are designed to promote a feeling of home, and to include dementia friendly elements and features that allow for activities, interests, abilities and skills to be maintained in ways that support an individual's feelings of security and belonging
- Person with dementia is always accompanied while in the community
- If person continues to drive, someone accompanies the person regularly to monitor driving skills and the safety of the vehicle
- Person's physical abilities, cognition and driving abilities tested in a driving evaluation

OUTCOME ONE: I have the best possible physical well-being

Indicator 6: I am safe *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<u>Interview</u> <ul style="list-style-type: none"> • Person reports feeling safe • Family reports being happy with level of safety the person has, safeguards in place, etc. • Person has balance of safety and autonomy that is monitored and adjusted as needed 	<ul style="list-style-type: none"> • Caregivers have the support they need to end person's driving if needed (e.g., Alzheimer's Assn.) • Caregivers are educated on how to adapt environments and activities, obtain products, etc. to increase person with dementia's safety, maintain abilities, etc.

Indicator 7:

My medical needs are being treated by people knowledgeable in dementia

Observable Measures:	Related Good Practice by Caregivers:
<u>Physical Measures</u> <ul style="list-style-type: none"> • Test results of ongoing screening, concurrent conditions, etc. 	<ul style="list-style-type: none"> • Person has been thoroughly screened for both chronic/progressive and reversible/treatable causes of dementia - assessments include neurological, psychological, medication, physical, nutritional, psychosocial (including relationships with caregivers, caregiving approaches) functional and environmental (home safety) screening. Ideally, diagnosis has been done by a physician who is a dementia specialist, or team of specialists (e.g., dementia diagnostic clinic) • Person has written diagnoses and recommended interventions, primary physician is collaborating with dementia diagnostic specialists, where available, about person's care • Person's concurrent health conditions are monitored and treated according to person's wishes, especially in regard to their impact on dementia symptoms
<u>Observation</u> <ul style="list-style-type: none"> • Person appears to be in good health and functioning well • Caregiver(s) appear to demonstrate knowledge of conditions and treatment or skills to administer, as needed to maintain person's health • Person's glasses and hearing aids are in good repair, person is using them • Person able to chew food comfortably 	<ul style="list-style-type: none"> • Caregivers are educated in all aspects of person's health care issues and interventions, information is written and shared between all caregivers and medical professionals in an ongoing team approach • System is in place for assuring that medications are taken appropriately • Complete list of current prescriptions and over the counter medications is maintained at home, by the physician and by the pharmacist • Teeth/dentures repaired when broken or lost

OUTCOME ONE: I have the best possible physical well-being

Indicator 7: (continued)

My medical needs are being treated by people knowledgeable in dementia

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Records</u></p> <ul style="list-style-type: none"> • Evidence that person has had a thorough screening for health conditions including dementia diagnoses and reversible/treatable causes • Diagnoses are being treated according to treatment plan, chronic conditions have documented routine monitoring and care • Person is receiving appropriate and prescribed medications and/or treatment • Regular Doctor visits and related changes in health interventions documented • Prescriptions are up to date/current – old ones are discarded or removed 	<ul style="list-style-type: none"> • All medications person is taking (including over-the-counter) are screened prior to use for potential drug interactions, and there is ongoing communication between all of person's health care providers whenever a medication or condition changes • Person is monitored for acute conditions, followed up with appropriate medical consultation • Routine dentist visits every 6 months or sooner if needed • Regular eye and hearing exams done • Family is involved in medical decisions with person's consent, power of attorney for health care has been assigned – activated at appropriate time, copy in person's records
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Person and/or caregiver can articulate medical needs and treatment • Family can attest to quality of person's health and medical care where known • Caregivers insure that family physician is carrying out plans recommended by dementia specialists 	<ul style="list-style-type: none"> • Person/caregivers have been educated about latest medications and supplements that can enhance cognitive function, clinical trials and brain donation • Caregivers maintain ongoing communication with person's physicians/team to provide updates on person's progress, especially when person is taking cognitive enhancing medication

Indicator 8: I receive the least restrictive intervention for my behavior symptoms

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Physical Measures</u></p> <ul style="list-style-type: none"> • Test results of screening for issues that could exacerbate person's behavior (e.g., bladder infection, illness, injury, dehydration, concurrent health problem, etc.) 	<ul style="list-style-type: none"> • Caregivers are educated to recognize that rapid changes in a person with dementia's behavior or cognition can indicate a potential underlying medical issue, and to have the person medically evaluated right away • Person's history of rapid behavioral or cognitive changes caused by medical issues is documented for future reference, including symptoms of onset, and shared with other caregivers, providers and/or family to provide future continuity of care and early response

OUTCOME ONE: I have the best possible physical well-being

Indicator 8: I receive the least restrictive intervention for my behavior symptoms *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person's environment has been arranged and adapted to allow freedom and safety, while minimizing situations that could cause distress • Person appears to be alert, responsive and able to participate appropriately as desired • Caregivers demonstrate ability to provide supportive, positive interaction with person while preventing escalation or triggers that would be distressing to person • Restraints are not observed to be in use 	<ul style="list-style-type: none"> • <u>Note:</u> Dementia behavioral symptoms are usually caused by an interplay between the person's chronic health conditions, current impairment of abilities, past experiences/coping strategies and the current environment. Successful strategies for supporting a person with dementia who is experiencing behavior symptoms will need to address all of these issues simultaneously. All behavior is a form of communication needing to be heard • <u>A problem solving process is in place to:</u> <ul style="list-style-type: none"> - Observe person's symptoms, environment, other's behavior/reactions, times of day, etc. during behavior - Record observations (more than one person is helpful) - Share information, develop hypotheses, define ideas and strategies to influence person's behavior and/or address person's underlying needs - Establish a shared, agreed upon strategy to implement ideas, include all caregivers. Repeat above process again observing the strategy, continue as needed. • <u>A process of ruling out potential contributing factors to the person's behavior symptoms is used,</u> starting from the person's internal and external environment, and moving to more complex interventions, e.g.: <ul style="list-style-type: none"> - Rule out (R/O) physical/internal causes – e.g., illness, pain, vision/hearing, dehydration, constipation, bladder infection (have person get a good diagnostic work-up if hasn't yet had one) - R/O external environmental causes – visual cues/triggers as reminders, temperature, noise, pace of activities, boredom, access to pacing area, need to engage in habits/routine, etc. (have a dementia-specific environmental safety evaluation done) - R/O caregiver approach causes – approaches using punitive or rewarding activities that don't recognize that person has lost short-term memory/learning ability, assuming person is doing things on purpose, etc. (see Caregiver Mentoring Tool for information/ideas) - Consultation with an M.D. who specializes in behavioral intervention - depression screening, psychiatric medications, etc. – especially if person has had a diagnostic screening and a baseline established, including screening for previous trauma/abuse

OUTCOME ONE: I have the best possible physical well-being

Indicator 8: I receive the least restrictive intervention for my behavior symptoms *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Records</u></p> <ul style="list-style-type: none"> Caregiver training to manage behavior symptoms has been received, documented Person's behavior symptoms and strategies for intervention/prevention have been identified, ongoing documentation of situations and person's Responses are present and have been shared with all caregivers Least restrictive medication is prescribed for person in records Use of restraints is not present -or if being used, appropriate prescriptions, evaluations and monitoring are documented 	<ul style="list-style-type: none"> Also see medical care indicator (previous indicator) Someone knowledgeable in home safety and adapting environments for persons with dementia has reviewed person's home/environment, recommended changes are made to increase safety and minimize behavior symptoms Person has been screened for life experiences involving trauma and abuse – information has been documented, shared and incorporated into strategy as underlying trigger to behavior symptoms – compensated for in intervention approaches Proactive strategies are put in place to prevent person from having to experience future behavior symptoms, once the strategies are identified Person's life history is recorded and used for developing hypotheses and potential influences/changes to address behavior symptoms - especially person's likes/dislikes, routines, interests, "repetitive themes", favorite music, comfort food, etc. (see outcome #4 for more details)
<p><u>Interview</u></p> <ul style="list-style-type: none"> Person interacts positively without agitation or appearance of being overly sedated Caregiver identifies person's previous (or current) symptoms, triggers and approaches being used to calm or prevent symptoms 	<ul style="list-style-type: none"> Caregivers/family members are educated about person's dementia and how it affects person's ability to function over time; encouraged to identify person's specific symptoms and coached on how to address them in supportive, positive and proactive ways utilizing person's life history and strengths. Caregivers are provided with ongoing support to do this. Caregivers learn how to track information about person with dementia and their symptoms/progress during periods of testing strategies, and share it with the physician/team Respite sources are identified and used, so family caregivers can care for themselves, receive ongoing education/support and have better ability to support person with dementia when having behavior symptoms - including targeted help (see outcome #2 page 18 for more details)



Outcome Number Two

As a person with dementia, I have meaningful relationships

1. I am supported in maintaining ongoing relationships as desired and
I am provided with opportunities to develop new relationships as desired

With:

- Family
- Friends and Peers
- Formal Caregivers
- Pets
- Other Generations

1. I have the opportunity to maintain an intimate* relationship with my spouse/partner as desired within my capacity

*(*intimate = physically and emotionally close, sexual as person's competency/consent allows)*



OUTCOME TWO: I have meaningful relationships

**I am supported in maintaining ongoing relationships as desired and
I am provided with opportunities to develop new relationships as desired
with:**

Indicator 1: Maintaining/Developing Desired Relationships with Family Members

Observable Measures:	Related Good Practice:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Interactions • Conditions • Observable nurturing contacts with family • Person displays and/or responds to warmth and affection 	<p><u>Facility</u></p> <ul style="list-style-type: none"> • Opportunities for family participation provided through special events, designated visit times, volunteer opportunities, etc. • Transportation available for person to attend family gatherings • Accommodations made available for family to visit and/or stay at the facility (or close by) • Support for family (e.g. information about dementia, regular updates, and activities to provide meaningful interactions during visits, etc.) is provided to keep them involved in person's life <p><u>Home</u></p> <ul style="list-style-type: none"> • Provide education/tools that can help facilitate meaningful activities between person and family members as person declines • Information about access to transportation, assistance with outings, etc. is provided
<p><u>Records</u></p> <ul style="list-style-type: none"> • Visiting hours accommodation of visitors • Frequency of contacts with family • Proximity or access to family • How often person attends normal family functions 	<ul style="list-style-type: none"> • Person's relationships and participation preferences with each of them are identified • Staff partner with the person and family to encourage and facilitate ongoing contact as part of the person's routine • Family remains involved in person's day to day decisions and updates as desired
<p><u>Interview:</u></p> <ul style="list-style-type: none"> • Person/family members report satisfaction with relationships, frequency and quality of contact • Family caregivers have support they need to maintain meaningful relationship with loved one 	<ul style="list-style-type: none"> • Family caregivers are informed of ways that targeted respite and/or assistance can provide help with activities caregivers find stressful or interfere with their "role", thus preserving the relationship with their loved one – e.g., bathing, personal care may put spouse or adult child into a feeling of being a "parent", may not want this shift in the relationship

OUTCOME TWO: I have meaningful relationships

Indicator 2: Maintaining/Developing Desired Relationships with Friends and Peers

Observable Measures:	Related Good Practice:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Interactions • Conditions • Observable activities done together • Person displays and/or responds to friends/peers • Facilitators of activities foster frequent peer interaction, person engages with peers beyond the activities too 	<p><u>Facility</u></p> <ul style="list-style-type: none"> • Sufficient & flexible visiting hours in facility • Opportunities for participation of friends provided through special events, designated visit times, volunteer opportunities, etc. • Regular activities are facilitated which are designed to foster interaction between peers and increase self esteem by celebrating each person's accomplishments <p><u>Home</u></p> <ul style="list-style-type: none"> • Caregivers are encouraged to maintain person's social relationships with friends as before, as long as possible • Referral or participation of person in organized community activities - in adult day setting, senior center, etc.
<p><u>Records</u></p> <ul style="list-style-type: none"> • Visiting hours/activity times • Frequency of contacts with friends/peers • Proximity or access to friends • How often person attends peer functions • Scheduled of events on calendar 	<p><u>Facility</u></p> <ul style="list-style-type: none"> • Activity groups between peers are facilitated according to a structure that invites people to participate, allows a turn for each person, celebrates each person's contribution and encourages positive interactions that build self-esteem (See "Spark of Life Program" ideas – Jane Verity, Dementia Care Australia) • Person is offered opportunities to regularly engage with peers, at the level of participation that s/he is capable of • Person is encouraged to attend activities/day services as a contributing volunteer and acknowledged for all s/he has to offer others when reluctant to attend as a participant
<p><u>Interview:</u></p> <ul style="list-style-type: none"> • Person/family members and/or friends report satisfaction with relationships, frequency and quality of contact • Person initiates or engages in pleasant peer to peer interactions 	<p><u>Home:</u></p> <ul style="list-style-type: none"> • Family caregivers are educated about resources that can be used to structure visits with friends and provide activities that foster meaningful interactions to keep them involved in person's life (e.g., Bi-folkal kits at library, activity kits/books for purchase, etc.)

OUTCOME TWO: I have meaningful relationships

Indicator 3:

Maintaining/Developing Desired Relationships with Formal Caregivers

Observable Measures:	Related Good Practice:
<u>Observation</u> <ul style="list-style-type: none"> • Caring/positive interactions observed between person with dementia and caregiver(s) • Caregivers display knowledge of person's life, needs, routines, preferences, etc. during interactions 	<ul style="list-style-type: none"> • Formal caregivers spend time to develop rapport and establishing a trusting relationship with the person, especially prior to providing personal care • Person has continuity of caregivers – same caregiver(s) consistently their providing care • Person is able to choose their caregivers wherever possible • Caregiver(s) and the person are able to continue relationships if caregiver leaves formal situation if desired and appropriate for the person
<u>Records</u> <ul style="list-style-type: none"> • Staff schedules/assignments • Customer satisfaction reports, comments of person about caregivers in records 	<ul style="list-style-type: none"> • Staffing patterns reflect accommodation of person with dementia's preference for caregivers, routine and stable pattern of same caregivers giving care (also see continuity of caregivers, Outcome #4)
<u>Interviews</u> Person/caregivers and family members report satisfaction with care and positive relationships with caregivers <ul style="list-style-type: none"> • Person's preferences for care and caregivers are met • Person and/or family share positives about formal caregivers, identify things they do that are meaningful 	<ul style="list-style-type: none"> • Caregivers are able to discuss person's care with family, be included to some degree in family visits • In some cases, family is able to maintain relationships with formal caregivers even after person with dementia declines/passes away

Indicator 4: Maintaining/Developing Desired Relationships with Pets

Observable Measures:	Related Good Practice:
<u>Observation</u> <ul style="list-style-type: none"> • Person appears to enjoy interactions with the pet(s) – allowed to participate at level s/he is comfortable with • Person reminisces about pets s/he enjoys 	<ul style="list-style-type: none"> • Opportunities for pet therapy/visits are offered to the person as s/he desires under safe, supervised conditions (e.g., family pet, planned activities with humane society or zoo, etc.) • Reminiscence activities about pets are offered
<u>Records</u> <ul style="list-style-type: none"> • Evidence that opportunity to interact with pet given - activity logs, visiting logs, etc. 	<ul style="list-style-type: none"> • Some facilities have live-in pets, person with dementia's wishes to interact or not are recorded, honored

OUTCOME TWO: I have meaningful relationships

Indicator 5:

Maintaining/Developing Desired Relationships with Other Generations

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Positive interactions between children and person with dementia Person is engaged in observing, contributing, giving/receiving affection, etc. 	<ul style="list-style-type: none"> Activities that pair young people with person are facilitated and offered e.g., singing, story telling, crafts, meals, as volunteers to help person, etc. Person participates in community or family activities that involve children, young adults, etc. if desired Person allowed to participate at the level s/he chooses
<u>Records</u> <ul style="list-style-type: none"> Activity logs Visiting logs 	<ul style="list-style-type: none"> Intergenerational activities regularly offered Person has opportunities to spend time with family members of other generations
<u>Interviews</u> <ul style="list-style-type: none"> Person/caregivers indicate that activities with other generations are enjoyed 	

Indicator 6:

I have the opportunity to maintain an intimate relationship with my spouse/partner as desired, within my capacity

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Provision for privacy Person displays or responds to warmth and/or affection from partner Person initiates contact with partner 	<u>Facility</u> <ul style="list-style-type: none"> Sufficient & flexible visiting hours in facility with policy or guidelines defined for conjugal visits
<u>Records</u> <ul style="list-style-type: none"> Policy/guidelines for private time and conjugal visits defined by facility Documentation of discussion with facility staff (private time and conjugal visit information) Possible records of number conjugal and/or private time visits 	<u>Facility</u> <ul style="list-style-type: none"> Information about conjugal visits is discussed with person and spouse/partner as part of orientation to facility Support for conjugal visits is provided through opportunities, adaptations, accommodations (e.g., facilitated phone use, large bed, private room, etc.) Private areas are available for spending time together to dine, watch TV, talk, etc. <u>Home:</u> <ul style="list-style-type: none"> Partner and person are able to receive support e.g., referrals for counseling, support groups medical specialists – to discuss changes in relationship, needs, competency issues Person's competency to consent to conjugal activity is respected (in any setting)

OUTCOME TWO: I have meaningful relationships

Indicator 6:

I have the opportunity to maintain an intimate relationship with my spouse/partner as desired, within my capacity *(continued)*

Observable Measures:	Related Good Practice:
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Person and partner indicate that they have opportunity and privacy for time alone together • Person and partner indicate knowledge and/or utilization of opportunity to have conjugal visits • Couple reports they are provided referrals for emotional, informational and medical support as needed • Partner demonstrates understanding of the level of person's competency, ability to consent/engage in conjugal activity 	<ul style="list-style-type: none"> • Spouse is educated by appropriate party to understand legal competency and consent issues if necessary



Outcome Number Three

As a person with dementia, I have hope because my future is valued and supported

1. I participate to my capacity in all decisions affecting my life
2. I am useful and make contributions of value
3. I plan and do things I've wanted to do while I still can
4. I have the emotional support and encouragement that I need
5. I regularly have positive things to look forward to and do
6. I have a legally supported plan for my future needs and wishes
7. My previous wishes are honored as my capacity diminishes
8. I continue practices that nourish me spiritually



OUTCOME THREE: I have hope because my future is valued and supported

Indicator 1: I participate to my capacity in all decisions effecting my life

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation:</u> <ul style="list-style-type: none"> Person's environment, routines, activities reflect personal interests and are commensurate with ability Caregivers offer choices 	<ul style="list-style-type: none"> Person is offered choices between two items so as not to overwhelm with too many choices Person is asked and invited to do things, not made to or told to
<u>Records:</u> <ul style="list-style-type: none"> Evidence that a capacity evaluation or competency exam has been done periodically, documentation provides details on types of decisions person can make on own vs. with supervision Person's surrogate decision-maker is the one that the person chose to make decisions, and s/he is indeed making them with input from or knowledge of the person 	<ul style="list-style-type: none"> Issues of autonomy are weighed against issues of person's safety, a balance is aimed for Competency and capacity evaluation is done with person periodically Powers of attorney are activated when appropriate Person chooses people to legally represent them as surrogate decision-makers
<u>Interviews</u> <ul style="list-style-type: none"> Evidence of input into decision making in POA documents, articulated plans, medical records, service plans, etc. 	<ul style="list-style-type: none"> Person w/dementia is involved in all decision making processes to their capacity, even if it's just asking opinions, discussing options, etc.

Indicator 2: I am useful and make contributions of value

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Person engaged in activities that they enjoy which contribute to others Items that the person has made or awards, certificates, etc. from others are visible 	<ul style="list-style-type: none"> Person engages in skill appropriate activities regularly that offer contributions to others, which are meaningful to the person Activities are designed to always have a degree of success and contribution KEY: Person's contributions are always acknowledged and s/he thanked for them, and told how they make a difference to others
<u>Records</u> <ul style="list-style-type: none"> Evidence that person's values, preferences have been discussed, recorded and incorporated in routine activities 	<ul style="list-style-type: none"> Types of usefulness (values) that are cherished by the person are identified (e.g.) <ul style="list-style-type: none"> - Others learn about my disease from me - Children can learn and witness life from me - Opportunity to give by participating in research

OUTCOME THREE: I have hope because my future is valued and supported

Indicator 2: I am useful and make contributions of value *(continued)*

Observable Measures:

Interviews

- Evidence that person is involved in adapted activities that parallel former activities which provide contributions to others/their home
- Caregiver can articulate/demonstrate useful activities person participates in

Related Good Practice by Caregivers:

- Person is able to participate/assist in tasks like cooking, caring for plants or pets, etc.
- Facility has a resident council that person can participate in, provide input
- Person is involved/has input into regular planning of group activities, topics, events, etc., that s/he participates in

Indicator 3: I plan and do things I've wanted to do while I still can

Observable Measures:

Observation:

- Items indicating person's wishes present in environment
- Memorabilia representing fulfillment of person's wishes is present, person encouraged to reminisce about the experiences

Related Good Practice by Caregivers:

- Person and family/caregiver/supporters have discussed person's wishes for things that s/he wants to do while s/he still has the capacity (e.g., special trip, special event, time with certain people, etc.)
- Efforts/plans have been made to carry out wishes, even if it is in the form of a modified activity that is within person's capacity

Records

- Activity records reflect person's wishes and activities

- Person has been given the opportunity to make a "wish list" of things that they want to do, plans have been made to support person's wishes

Interviews

- Person and caregiver/family can share person's wishes and plans/activities

- Person has been encouraged and supported in discussing wishes/dreams, they are acknowledged, discussed and possibilities explored for fulfillment

Indicator 4: I have the emotional support and encouragement that I need

Observable Measures:

Observation

- Person expressing range of emotions appropriate to situation
- Person shows evidence of offering a unique contribution from themselves into the situation – not just doing it routinely

Related Good Practice by Caregivers:

- Validation approach used by caregivers – acknowledging person's feelings and allowing them to discuss them, regardless of the realism of his/her perspective
- Questions to the person are asked about how they feel – not quizzed about reciting facts

OUTCOME THREE: I have hope because my future is valued and supported

Indicator 4: I have the emotional support and encouragement that I need *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Praise and encouragement, compliments used by caregivers 	<ul style="list-style-type: none"> Caregivers understand grief process and allow person to experience his/her grief Caregiver understands that person can be triggered to re-live traumatic memories – knows how to work with person's triggers and avoid/redirect trauma
<u>Records</u> <ul style="list-style-type: none"> Evidence that person's emotions are discussed and acted on Problem solving approaches that are tried are documented for situations causing the person frustration 	<ul style="list-style-type: none"> Person has opportunities to participate in activities specifically designed to facilitate emotional expression and provide outlets for feelings Person has been screened for past emotional trauma, or known traumas have been documented Counseling referral where appropriate Close friends/family/staff who are "confidantes"
<u>Interview</u> <ul style="list-style-type: none"> Person expresses emotions through body language, expression, gestures, inflection and tone – even if unable to speak coherent words or sentences 	<ul style="list-style-type: none"> Person is encouraged to express feelings, even if non-verbal, feelings/communication is acknowledged, person thanked for sharing

Indicator 5: I regularly have positive things to look forward to and do

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Person identifies or responds favorably to discussion about an upcoming favorite activity Person is encouraged by caregivers to look forward to things they enjoy, and share feelings about things that have recently happened 	<ul style="list-style-type: none"> Person has a calendar in room where upcoming events are logged and referred to when person asks questions (e.g., family visits or outside gatherings, outings, favorite activities, etc.) Family/visitors write person a note/card at the end of visit/outing with the person describing the activities they did together, and referring to a future time when they will be back. Note is read to person and left in a prominent place (e.g., bulletin board) where person can refer back to it and remember the visit
<u>Records</u> <ul style="list-style-type: none"> Evidence that person is looking forward to upcoming visits, activities, etc 	<ul style="list-style-type: none"> Things that the person really enjoys are part of the person's routine, referred to by caregivers as an upcoming fun event to build person's anticipation
<u>Interviews</u> <ul style="list-style-type: none"> Person/caregivers/family can identify person's favorite anticipatory activities, however small or simple 	<ul style="list-style-type: none"> Caregivers are trained to share person's favorite anticipatory activities with each other and family to and ways to reinforce person's enjoyment

OUTCOME THREE: I have hope because my future is valued and supported

Indicator 6: I have a legally supported plan for my future needs and wishes

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Copies of advance directives and/or plans are available/in records, with guardian and person's doctor 	<ul style="list-style-type: none"> Person has been consulted in detail about their future wishes, been supported to develop a plan, and it has been documented with person signing it Plans can include details of living arrangements desired, people person wants to live with, elements in their desired routine, etc.
<u>Records</u> <ul style="list-style-type: none"> Person has advance directives, POA for Health care and finances, or a guardianship in place Have a written plan for future wishes 	<ul style="list-style-type: none"> Health care wishes are reflected in legal Power of Attorney documents and shared with all health care providers, caregivers and family members involved in person's care. POA documents on file at hospital and with doctor, family has a copy Person's financial plans and preferences are also documented on legal POA, copies are with appropriate parties and in person's records
<u>Interviews</u> <ul style="list-style-type: none"> If possible, person can name details of wishes, who is carrying them out, etc. POA representative/guardian, caregivers and person can articulate person's wishes 	<ul style="list-style-type: none"> Powers of attorney for health care and finances are activated when appropriate Alternate POA representative or guardian is kept informed of decisions and issues in person's care

Indicator 7: My previous wishes are honored as my capacity diminishes

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Plans being carried out are ones indicated in person's records 	<ul style="list-style-type: none"> Support is offered to caregivers/guardians to help them carry out difficult decisions, including hospice grief counseling
<u>Records</u> <ul style="list-style-type: none"> Records show evidence that advance directives and previous wishes are being followed 	<ul style="list-style-type: none"> Powers of attorney for health care and finances are activated when appropriate, Secondary POA persons/guardians are also notified of decisions and issues in person's care
<u>Interviews</u> <ul style="list-style-type: none"> Care providers report understanding of person's directives and wishes, demonstrate how they are being followed 	<ul style="list-style-type: none"> New care providers are informed of person's wishes as soon as they begin work with the person Caregivers are offered the hospice support they need for end of life care

***OUTCOME THREE: I have hope because my future is valued
and supported***

Indicator 8: I continue practices that nourish me spiritually

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Person engaged in spiritual practices that they enjoy 	<ul style="list-style-type: none"> Person is encouraged to engage in spiritual practices by caregivers, including activities that reflect a variety of spiritual practices
<u>Records</u> <ul style="list-style-type: none"> Evidence of opportunities, engagement in spiritually fulfilling activities that person has identified 	<ul style="list-style-type: none"> Person's spiritual practices are identified, incorporated into their daily/regular routine
<u>Interviews</u> <ul style="list-style-type: none"> Person and/or caregivers can describe meaningful activities, spiritual activities and experiences, and the benefits person gets from participating in them 	<ul style="list-style-type: none"> Person's participation in spiritual practices can have positive effects, e.g., relaxation, feelings of well-being, health benefits and enjoyment



Outcome Number Four

As a person with dementia, I am accepted and understood as an individual

1. I am treated as a person not a disease, and am acknowledged as “present”
2. I am cared for by people who understand me, and about my dementia
3. I have regular opportunities to access and share my rich & meaningful past
4. I practice rituals that comfort or calm me
5. I continue my own cultural lifestyle
6. My orientation to time and reality is respected and supported
7. I continue my familiar routines
8. My environment is anchored in things I value that are familiar to me
9. I have continuity in relationships with caregivers
10. I have physical privacy
11. My sexual identity is treated with respect
12. I am free from all forms of abuse



OUTCOME FOUR: I am accepted and understood as an individual

Indicator 1:

I am treated as a person not a disease, and am acknowledged as “present”

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person is called by preferred name • Others pay attention to person regularly, i.e. eye contact and conversation, interaction • Address person directly not those around the individual • Terms used to describe disease are not used to describe person (e.g., not called “feeder”) • Communication techniques to build self-esteem and confidence are used • Person is responsive and engaged in positive ways with staff, caregivers, peers etc. • Person’s actions are purposeful, meant to influence situation 	<ul style="list-style-type: none"> • Person is always greeted and invited to engage • All of person’s responses and initiations of contact – regardless of type – are acknowledged and responded to in the most positive way possible • Caregivers talk through the care they are doing as they are going to do it, especially if they leave person’s line of vision • Person is always asked for permission beforehand - to be touched, have clothing adjusted etc. within their personal space and/or to do something in their room or with their belongings – person’s response is honored and talked through with them • Meaning of person’s communication is paraphrased back to them to clarify understanding, invite further response • All of person’s efforts are celebrated and valued with a rewarding acknowledgement (compliment, touch, clapping, laugh, smile, etc.) • Person is thanked for the conversation/contribution at conclusion of interaction
<p><u>Records</u></p> <ul style="list-style-type: none"> • Staff/caregivers etc. have been trained in positive communication techniques • Documentation and care planning reflect person’s responses, preferences, improvements in communication, interactions, etc. 	<ul style="list-style-type: none"> • Training and modeling of above techniques done consistently for caregivers – learn by example • Person is treated as an adult, not as a child to be corrected or punished
<p><u>Interviews</u></p> <ul style="list-style-type: none"> • People who regularly interact with the person can articulate and demonstrate positive communication techniques (see good practice column), give examples of person’s thoughts, feelings, reactions, etc. to things 	<ul style="list-style-type: none"> • Caregivers report learning from each other and the person about effective communication • Caregivers are comfortable in letting person guide communication • Gestures, sounds, movements etc. become part of the language between person and caregivers

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 2: I am cared for by people who understand me, and about my dementia

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Caregivers make accommodations for person, adjust their techniques and interactions to fit person's needs 	<ul style="list-style-type: none"> Caregivers and family are educated to be knowledgeable about the person's specific type of dementia and how it effects the person and their abilities/behavior Information shared between staff, family – updated as new information is learned about the person
<u>Records</u> <ul style="list-style-type: none"> Written information about the person's individual needs, effective approaches and accommodations, etc. are evident 	<ul style="list-style-type: none"> Caregivers ask questions about the person's thoughts and feelings on things instead of quizzing about facts/names, etc. (quizzing emphasizes person's weakest skill/disability, which is memory for facts) Person's orientation to reality is respected
<u>Interviews</u> <ul style="list-style-type: none"> Caregivers can identify person's dementia type and how it effects person, successful ways of accommodating to person's needs 	<ul style="list-style-type: none"> Caregivers/family members are educated about person's dementia and how it effects person's ability to function over time; Caregivers/family encouraged to identify person's specific symptoms and coached on how to address them in supportive, positive and proactive ways utilizing person's life history and strengths

Indicator 3: I have regular opportunities to access and share my rich & meaningful past

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Evidence that person spends time reminiscing with others People are interacting with person about things that are unique to him/her in regular conversation Personal history is written, reflected in care planning Person's environment contains items that reflect her/his past Person has a "life story book" that s/he uses to reminisce 	<ul style="list-style-type: none"> Person's life story reflecting the essence of who they are is recorded - with likes, dislikes, routines, hobbies, interests, meaningful experiences and people, past traumatic events, "repetitive themes", favorite music, comfort food, etc. – and shared with all caregivers to degree person prefers Significant items connecting the person to their past (e.g., photos, furniture, favorite quilt, awards, medals, memorabilia, etc.) are displayed in person's environment to prompt them to reminisce about her/his past, share with others A "life story book" is created for person that reflects photos and information about important events and people in her/his life Person's habits, routines, preferences, values, beliefs, behavior symptom triggers, etc. are respected, positively supported and accommodated during periods of change, stress, etc.

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 3:

I have regular opportunities to access and share my rich & meaningful past

Observable Measures:	Related Good Practice by Caregivers:
<u>Records</u> <ul style="list-style-type: none"> Staff/caregiver training in reminiscence Evidence that “life story book” activity is used regularly Evidence of routine being a personal preference in care plan, documentation. (e.g., prefers to bathe in evening) 	<ul style="list-style-type: none"> Person is encouraged to reminisce daily Person’s environment displays treasured items that trigger reminiscence, feelings of belonging etc. and sharing of who they are Person’s life history has been documented – major events, people, places, hobbies, clubs, spiritual practices, activities of enjoyment, traumas, etc., and information is reflected in meaningful interactions and opportunities for engagement
<u>Interview</u> <ul style="list-style-type: none"> Caregivers can articulate personal history Person reminisces, articulates important things to them that are reflected in current lifestyle 	<ul style="list-style-type: none"> Caregivers understand when a person may be oriented to a past event, realize the past has current value to the person and respond accordingly by entering the person’s world with them

Indicator 4: I practice rituals that comfort or calm me

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Rituals are practiced by person as usual, used to calm person in times of stress Person requests to do ritual Items on hand to engage in ritual Caregivers provide guidance/prompting 	<ul style="list-style-type: none"> Rituals that have meaning, have been practiced routinely for the person’s life are identified and supported (prompts to do, documented part of routine, etc.) Tools and processes for the rituals have been identified and are accessible to the person, especially at times usually practiced (e.g., rosary before bed, special music to relax, morning coffee and magazine, etc.) Staff/caregivers knowledgeable of the rituals and their practice, when to offer them/provide prompts
<u>Records</u> <ul style="list-style-type: none"> Evidence that person has been able to participate in rituals routinely Person has body relaxation after practicing ritual 	<ul style="list-style-type: none"> Rituals are incorporated into person’s care plan Person’s responses to ritual are noted – indicated as part of a calming strategy
<u>Interviews</u> <ul style="list-style-type: none"> Caregiver can articulate rituals that are important 	<ul style="list-style-type: none"> Person’s ritual routine is respected by caregivers, referred to if person becomes agitated to see if it was missed, altered or if it could be initiated to calm person

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 5: I continue my own cultural lifestyle

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> • Evidence that person is practicing their cultural activities • Caregivers support and encourage/use cultural practices • Person shares information about culture with others 	<ul style="list-style-type: none"> • Person's cultural practices are identified (e.g., use of kosher dishes, observance of holy times, types of food eaten/not eaten, attire, social customs/hierarchies, ways of addressing person when they are spoken to, etc.) • Person is invited to share their cultural practices and history with others
<u>Records</u> <ul style="list-style-type: none"> • Documentation of cultural preferences, practices • Evidence that practices are known by caregivers and practiced 	<ul style="list-style-type: none"> • Practices that are important to the person and family are recorded, staff is trained in them • Person's languages, food, beliefs, clothing, social practices, how person is addressed, holidays, beliefs about healing/illness are respected
<u>Interview</u> <ul style="list-style-type: none"> • Cultural practices are known by caregivers and practiced • Person/family report culture is respected, utilized and practices encouraged 	<ul style="list-style-type: none"> • Family members are encouraged to educate caregivers and others on person's culture • Person is encouraged to share her/his uniqueness cultural with peers, caregivers, etc. in planned activities • Facility practices are sensitive to person who's religion/beliefs are not those of the majority of the residents

Indicator 6: My orientation to time and reality is respected and supported

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> • Interactions between caregivers and person are respectful and validating • Person encouraged to "tap into" positive memories from the past 	<ul style="list-style-type: none"> • Validation approach used by caregivers when person communicates with them about the past • Person expressing feelings from the past which are being experienced as the present are validated and responded to in the context person understands them to be in • Person's previous experiences with trauma are taken into account when responding to person's concerns – feelings are acknowledged and supported • Important positive experiences in person's past are referred to as a way to help person create positive experiences in the present

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 6: My orientation to time and reality is respected and supported *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<u>Records</u> <ul style="list-style-type: none"> • Indications of caregiver training on techniques • Significant experiences from persons past are noted, strategies to address them indicated 	<ul style="list-style-type: none"> • Caregivers are trained in validation techniques and/or other ways to support person's orientation to time past/present (see Parenting to Caregiver model) • Person engages in age-appropriate adapted activities that reflect their previous roles
<u>Interview</u> <ul style="list-style-type: none"> • Person able to comfortably move between past and present experiences • Caregivers can identify validation concepts, and person's significant time shifts, ways person is supported 	<ul style="list-style-type: none"> • Caregivers learn effective ways to relate to person and accommodate person's shifts in reality by example and by working with person • Caregivers model effective techniques to others • Person is treated like an adult, and encouraged to reminisce about the past instead of being corrected

Indicator 7: I continue my familiar routines

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> • Person's routine reflects familiar habits, schedules, etc. • Person participates in parts of own care/routine to their highest ability • Caregivers use person's familiar ideas, topics, etc., to frame information when conversing with person 	<ul style="list-style-type: none"> • Familiarity is person's anchor to safety and feeling secure – environment and routine reflect the familiar • Changes that are introduced are incorporated into person's familiar structure (e.g., new clothes are placed out in morning, meal/rest times are kept consistent while traveling, familiar and trusted person introduces new caregivers, etc.) • Use of person's formal business titles or "Mr./Sir-Mrs./Madame" to address them
<u>Records</u> <ul style="list-style-type: none"> • Evidence that the person's familiar routines and experiences have been documented in assessments and updated as more information is learned • Evidence that daily /ongoing activities reflect person's preferences and routines 	<ul style="list-style-type: none"> • Person's preferred & essential routines are recorded and practiced • Caregivers are consulted for information about person's routines, particularly when person is having difficulties and the information could provide strategies • If person practices a faith, person continues to attend religious services or services come to them
<u>Interview</u> <ul style="list-style-type: none"> • Caregivers can articulate person's routines and importance, and the consequences for the person when deviations occur from routines 	<ul style="list-style-type: none"> • Person's routine preferences are confirmed when interruptions lead to different consequences, caregivers take the time to identify and realize this

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 8: My environment is anchored in things I value that are familiar to me

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person shows signs of being comfortable, being able to navigate easily and safely • Person reminisces about pictures and memorabilia in room • New environments reflect same room arrangements, familiar items, routines, etc. • Person able to perform previous job related tasks as part of routine • Picture/word/arrow cues are visible on drawers, cabinets, closets, near bathroom, and/or outside person's room as identifier 	<ul style="list-style-type: none"> • Beloved items are transferred to new/temporary environments along with the person (e.g., hospital, respite, while traveling, etc.) • Moves are done when the person can still adjust to change • Person's room/quarters are arranged to look as much like "home" as possible when person is moved (e.g., furniture arrangements, pictures on the walls, etc.) • Environmental adaptations/accommodations are made to assist the person in being able to safely continue participating in regular routines (e.g., creating "job" area the person can "go to work" at daily, modifying kitchen and bathroom with assistive equipment, etc.) • Environment is simplified, organized and clutter removed to reduce confusion • Navigational cues help person with way-finding • Person has places to rummage, keep their own belongings, and claim as her/his "space" (e.g., own chair, drawers or closets, etc.)
<p><u>Records</u></p> <ul style="list-style-type: none"> • Evidence that a safety evaluation was done and recommended equipment purchased or installed • Evidence that parts of environment were adapted specifically to meet person's needs 	<ul style="list-style-type: none"> • Safety evaluation is done if person is living in a place where accessibility issues have not been addressed • Person's environment is changed/equipped to eliminate dangers that could cause falls, add equipment that would help person to maintain balance and safety (see Home Safety Evaluation tools) • Ideally – person with dementia in a facility does best when s/he has own room
<p><u>Interviews</u></p> <ul style="list-style-type: none"> • Person and/or caregivers express person is comfortable and safe in their environment, able to continue to care for self and do the things s/he likes to do • Person refers to dwelling as "home" 	<ul style="list-style-type: none"> • Person's living arrangement reflects the essence of home for her/him, feels comfortable there • Person can engage in activities s/he enjoys in their own space (T.V., music, etc.)

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 9: I have continuity in relationships with caregivers

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person/caregiver have rapport, common shared experiences they refer to and positive regard for each other • Person responds appropriately to caregivers • Person expresses self, makes wishes known 	<ul style="list-style-type: none"> • When person meets new caregivers, they are introduced by someone the person trusts and the three of them are able to talk and build rapport/trust with new caregiver • New caregivers shadow the person's primary caregiver to learn routines, and to perform caregiving techniques while being supported and guided • The person is encouraged to develop positive relationships with caregivers - asked to provide instructions, opinions, share feelings, etc. •
<p><u>Records</u></p> <ul style="list-style-type: none"> • Substitute caregiver information easily accessible • Caregiver training records indicate relationship skill building • Staff turnover • Person's emergency contact information • Documentation of regular caregivers and their communication with each other 	<ul style="list-style-type: none"> • Detailed information about the person's routine is written and easily available to substitute caregivers • The same primary caregiver – who the person trusts - provides all of the person's personal care • The same caregiver or caregivers provide care to the highest extent possible • Caregivers routinely share information across disciplines, shifts, settings etc., reinforce their communication with the person and family • An advocate or substitute caregiver is always available in cases of emergency; other caregivers, family members, etc., know whom this person is and how to contact • Facility and substitute caregivers are trained on ways to build rapport with people who have dementia (discuss common or shared history, compliments, asking for person's ideas/opinions, inviting not telling or directing, etc.)
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Person and family identify regular caregivers and substitute caregivers, means of access and routine communication 	<ul style="list-style-type: none"> • People who are trusted and familiar to the person – family, friends, previous caregivers etc. are utilized to provide care whenever possible • Person is able to maintain relationships with previous caregivers after transition where possible and desired • Caregivers/person can identify who the emergency contact person is and how to contact

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 10: I have physical privacy

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Adequate doors, curtains used when dressing, toileting, bathing, grooming Person is dressed/covered appropriately, especially when wet or when the environment is cold/chilly 	<ul style="list-style-type: none"> Person's privacy in the environment is respected and protected by others When person is given a shower or bed bath, parts of the body that are exposed and not being washed are covered Person is allowed to go to the toilet without being observed, though caregiver should be nearby to assist person when s/he asks/needs Person has time alone and personal space to spend it in Person's belongings are secure, not gone into unless person consents Person is always adequately dressed in the company of others/out in public
<u>Records</u> <ul style="list-style-type: none"> Evidence of person's privacy preferences 	<ul style="list-style-type: none"> Person's privacy preferences are documented, known by caregivers (e.g., not to enter the room during night-time bed checks, privacy with visitors, etc.)
<u>Interview</u> <ul style="list-style-type: none"> Person/caregivers can identify times during person's routine when person has privacy (e.g., time alone, with visitors, allowed to engage in activities of her/his choice) 	<ul style="list-style-type: none"> Person is allowed to engage in activities of her/his choice when alone or with visitors within safety parameters

Indicator 11: My sexual identity is treated with respect

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Interactions with others involving touch, affection 	<ul style="list-style-type: none"> Person is directed to or given privacy when aroused – alone time or time with spouse/partner as appropriate Communication that fills needs for touch and affection that is non-sexual in nature is present to fill emotional needs Persons that are redirected are done so with respect and acknowledgement of their cooperation
<u>Records</u> <ul style="list-style-type: none"> Facility policies Person's records 	<ul style="list-style-type: none"> If person resides in a facility, policy and practice reflects respectful accommodations for continuing sexual relationships, as well as considerations for communicating with family/guardians and assessing competency when new relationships evolve in facility

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 11: My sexual identity is treated with respect

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Records</u> (continued)</p> <ul style="list-style-type: none"> • Evidence of issues person has had, discussions, strategies used, and approaches tried, results, etc. • Evidence of counseling/referral to others about concerns 	<ul style="list-style-type: none"> • If person seems to be “inappropriately behaving sexually”, the situation is examined for a variety of factors which could be influences (e.g., trying to communicate a bladder infection, clothing being too warm, brain chemical imbalances, etc.) • Person’s sexual orientation is treated with respect
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Person and/or partner report support for continuing sexual relationship, concerns, etc. • Caregivers can identify issues person has had, measures that have been taken to assist her/him 	<ul style="list-style-type: none"> • Person is given opportunities to discuss sexual concerns, needs, questions etc. with someone they can trust who can assist (e.g. social worker, nurse, physician, etc.)

Indicator 12: I am free from all forms of abuse

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • No restraints in use • Person appears to be wide awake etc. (not drugged) • Person free of bruises, injury • Interactions with others are positive, respectful • Person exhibits evidence of self respect - trying to preserve dignity, modesty • Person appears to have adequate clothing, nourishment, medical treatment, support, assistance, etc. 	<ul style="list-style-type: none"> • Use of physical or chemical restraints is absent • Person is free from restraints including sedating medication, tied restraints that person cannot undo, being placed in a recliner without ability to get out, having bed rails up that person cannot lower without assistance, solitary confinement, and other situations as mandated by state and federal laws • All areas of person’s body are checked during exams/assessments, checks are done routinely in frequent intervals throughout the week, and after visits or person’s complaints of injury/accusations of abuse (especially area’s on person’s back and places frequently covered by clothing – these areas are most likely places for abuse to be done) • Person has all of the basic needs met – for food, clothing, shelter, money, etc.

OUTCOME FOUR: I am accepted and understood as an individual

Indicator 12: I am free from all forms of abuse

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Medical issues and assistance needs identified and how regularly addressed documented • Accounting for person's finances is in order • Advance directives and Powers of Attorney are identified and/or implemented • Record of trauma assessment, information reflected in care plan 	<ul style="list-style-type: none"> • Person's behavior appears to be appropriate for her/his situation – inappropriate behavior is investigated for causes (e.g., overly sexual advances, or withdrawal and recoiling from touch could mean current or past sexual abuse, physical abuse, repeating foul language could mean previous verbal abuse, etc.)
<p><u>Records</u></p> <ul style="list-style-type: none"> • Medication records in order, no gaps or missing information, all medications in use accounted for, etc. • No medical reports of preventable injuries • Staffing patterns • Person's complaints, results of exams, pictures, others involved, referrals made to police/adult protective services/elder abuse agency, etc., are all documented in file • Staff training records have evidence of staff training/knowledge of what constitutes abuse 	<ul style="list-style-type: none"> • Person is adequately supervised • Medication records reflect appropriate timing, dosing, etc., and lack of medications used as restraints • All allegations of abuse, made by any person/staff/family member/caregiver, etc., are taken seriously and followed up on according to Adult Protective Services/Elder Abuse and criminal laws • All staff/caregivers are trained in how to recognize and report abuse according to law • In cases where a person makes repeated accusations of abuse which have been investigated and found to be false, consultation has been done with supervising agency (e.g., county) and a strategy agreed upon and documented as to how to handle future situations • Person's previous life traumas have been identified and documented along with potential stressors that could be triggers, information has been incorporated into person's plan of care
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Staff/caregivers can articulate and demonstrate philosophy of care • Person can articulate all types of abuse, answer to examples and identify if present or not, including sexual, financial, physical, emotional, etc. • Person/family can identify ways to contact advocacy channels, ombudsman, etc., for help 	<ul style="list-style-type: none"> • In a Facility – there are a set of guiding philosophy and value statements being practiced that specifically recognize person with dementia as being respected, valued, meaningfully engaged, etc. This is reflected in staff behavior, environment, routines, activities, etc. • Staff/caregivers are educated about ethics, have regular, structured, facilitated conversations about ethical issues as part of ongoing training • Person/family educated about what constitutes abuse where possible, and asked about it, when admitted into the care of any agency

**OUTCOME FOUR: *I am accepted and understood
as an individual***

Indicator 12: I am free from all forms of abuse *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Interview (continued)</u></p>	<ul style="list-style-type: none"> • Person is asked about specific acts of abuse when interviewed, e.g., biting, pinching, inappropriate touch, foul language, being restrained or put into dangerous situations, etc, (elderly people in some cases are not aware of all the aspects of abuse under current laws) • Person and family informed of advocacy channels, ombudsman, and how to contact appropriate places/people for help

Outcome Number Five

As a person with dementia, I am involved in life

1. I engage in activities that are meaningful to me daily
2. I have the opportunity to participate in the life of my community
3. I am able to communicate with others to my highest capacity
4. I am able to do things independently with safe supports
5. I enjoy the tastes, smells, sounds, and feelings of the real world
6. I have the opportunity to enjoy/be outdoors



OUTCOME FIVE: I am involved in life

Indicator 1: I engage in activities that are meaningful to me daily

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Person volunteers her/his input Person shows ability to focus on tasks, make a contribution and delight in results Person exhibits sense of humor Person shows evidence of putting “self” into situation, acting creatively 	<ul style="list-style-type: none"> Activities to elicit creative expression and facilitate interaction are part of the person's daily routine Person participates in a structured ongoing planned group activity (e.g. “club”, adult day services, etc.) which creates a “container” for experience through regular meeting times, invitation to participate, predictable interactive activities, celebration of person's contributions, peer sharing, laughter, etc.
<u>Records</u> <ul style="list-style-type: none"> Person's care plan, activity records Attendance records 	<ul style="list-style-type: none"> Activities that are meaningful to the person are identified and worked into the care plan or daily routine Joyful opportunities are part of person's life Have activities offered that are reflected in personal items & memorabilia. Family caregiver is provided with information/referral to day services, respite groups, in-home activity services, etc., that the person in her/his care can participate in

Indicator 2: I have the opportunity to participate in the life of my community

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Person's attendance, participation in community activities/events/gatherings Newsletters, cards, awards, certificates, etc. 	<ul style="list-style-type: none"> Person can perform citizenship duties (e.g. vote, be on resident or participant councils as able, etc.) Supervised transportation is available Connection to “systems” such as family, spiritual worship, etc.
<u>Records</u> <ul style="list-style-type: none"> Evidence of participation in social activities Records documenting participation (e.g., voting registration, minutes of meetings, etc.) 	<ul style="list-style-type: none"> Financial resources are available for the person to pay for transportation, cost of activities, memberships, etc. Activities that the person cannot go out to participate in are modified and brought in to the person
<u>Interview</u> <ul style="list-style-type: none"> Person/friends/family report continued participation 	

OUTCOME FIVE: I am involved in life

Indicator 3: I am able to communicate with others to my highest capacity

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person is engaged in conversation and communication • Person's communication is acknowledged and responded to by others • Person able to make wishes known • Person initiates contact with others • Person responds appropriately to others • Person is purposeful in actions • Has adaptive equipment or items needed and is using them 	<ul style="list-style-type: none"> • Communication with others is facilitated (within the person's capacity) • Opportunities to engage the person in communication are frequent and ongoing • Person using adaptive equipment needed, (e.g., glasses, hearing aids, etc.) • <u>Mid to later stages:</u> caregivers talk through care they give, ask the person questions and paraphrase the meaning of the person's sounds, body language/responses to verify person's message • Person's actions of communication are acknowledged by caregiver's words, body language, voice tone, etc. • Others' responses are verbalized to the person if s/he has trouble seeing or hearing response
<p><u>Records</u></p> <ul style="list-style-type: none"> • Evidence of use/need for/purchase of adaptive aids • Records of routine evaluation 	<ul style="list-style-type: none"> • Communication aids are used to help person express thoughts and needs, e.g., pain scales with smiley and sad faces, pictures and words, etc. • Person receives regular evaluations of sight and hearing
<p><u>Interview</u></p> <ul style="list-style-type: none"> • Caregivers report ways person communicates and what person communicates 	

Indicator 4: I am able to do things independently with safe supports

Observable Measures:	Related Good Practice by Caregivers:
<p><u>Observation</u></p> <ul style="list-style-type: none"> • Person has a balance between safety and autonomy • Person appears to be safe and capable 	<ul style="list-style-type: none"> • Systems for monitoring the person are in place and person is checked on daily (e.g., neighbors, family, mail and paper carriers, service providers, volunteer phone checks – all have a way to check on person and share information with a central person who is responsible for oversight) • Person's driving is evaluated, person is accompanied by someone competent while driving periodically if s/he can drive • Person is allowed to perform parts of tasks that s/he is still able to do, (e.g., cook with microwave instead of stove, sign checks, mix pre-measured ingredients, etc.)

OUTCOME FIVE: I am involved in life

Indicator 4: I am able to do things independently with safe supports *(continued)*

Observable Measures:	Related Good Practice by Caregivers:
<u>Records</u> <ul style="list-style-type: none"> • Evidence of pre-planning for decision points • Documentation of emergency/alternate plans 	<ul style="list-style-type: none"> • Red flags or decision points have been established in advance which indicate that the person's living situation needs to be re-evaluated and changes made • Alternate/emergency arrangements have been made in advance for times when more supervision may be needed • Caregivers are trained in task breakdown to assist with risky parts of tasks without taking over
<u>Interview</u> <ul style="list-style-type: none"> • Person reports that s/he can still do things that are important • Caregivers can identify plans that are in place, alternate plans and decision points 	

Indicator 5: I enjoy the tastes, smells, sounds, and feelings of the real world

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> • A variety of tastes, smells, sounds, textures and touch are present • Evidence that sensory stimulating activities are taking place, especially in later stages • Evidence that person's day has a varied pace of activity 	<ul style="list-style-type: none"> • Caregivers offer communication through touch, smell, music, movement, taste, sound, etc. especially during later stages of decline • Activities are designed to involve all of the senses, bright colors, music, etc. • Person's day is paced with times of high activity and lower key activity to avoid both over stimulation and sensory deprivation
<u>Records</u> <ul style="list-style-type: none"> • Activity records • Training records 	<ul style="list-style-type: none"> • Caregivers are trained in modalities of sensory activities
<u>Interview</u> <ul style="list-style-type: none"> • Person shows/reports enjoyment of sensory activities 	<ul style="list-style-type: none"> • Sensory activities take the place of verbal communication at times

OUTCOME FIVE: I am involved in life

Indicator 6: I have the opportunity to enjoy/be outdoors

Observable Measures:	Related Good Practice by Caregivers:
<u>Observation</u> <ul style="list-style-type: none"> Person is physically outside 	<ul style="list-style-type: none"> Opportunities to be outdoors and to go on outings are routinely offered Safe, accommodating outdoor places are available
<u>Records</u> <ul style="list-style-type: none"> Access to outdoors Daily schedule or records indicate time outdoors is available 	<ul style="list-style-type: none"> The value of nature to the person defined - incorporated into her/his surroundings (e.g., plants, murals, bird-feeders, pictures, etc.) Person can sit by windows and look out at the landscape for relaxation
<u>Interviews</u> <ul style="list-style-type: none"> Person/caregivers describe types of outdoor activities person enjoys, participates in 	<ul style="list-style-type: none"> Outdoor activities are modified to be done indoors (e.g., green house, water activities, miniature golf)

APPENDIX

APPENDIX

Procedure for Using the Dementia Outcomes Care Planning Tool

The following guidelines are recommended by the providers who piloted this tool.

Who to Involve: This tool has had the most success when used collaboratively across all levels of an organization, and when all members of the care team had input.

- Providers of direct caregiving
- Supervisors of direct caregivers
- Nurses
- Managers or those who allocate resources
- Person with dementia
- Family members/guardians
- County/government care managers

Time Allocation: The processes involved in initial training on the tool and related good practice, and the initial care planning take time. The stakeholders in the process need to be able to make a time commitment up front for:

- Education of team members on good practices, especially direct caregivers supervisors and nurses (approximately four hours).
- Time for the team members to read and review the tool in its entirety (approximately two hours), while considering the person with dementia's needs.
- Collaborative planning meetings for team members to discuss and construct the care plans (suggested one - two hours per week).
- Ongoing, regular collaborative meetings to review progress and adjust care plans quarterly.

Initial training on good practices should involve direct caregivers, supervisors and nurses with the option of county care managers/social workers attending. Some agencies also involved the CEO/owner of the agency resulting in good support for implementing the outcomes. Team members reported reading the tool individually and then coming together as a group to discuss their recommendations and negotiate the care plan. Family members and persons with dementia were invited into a shorter discussion of the care plan options with the team as a follow-up.

Teams reported that the initial outlay of planning time resulted in a much smoother and more thorough process taking less time at subsequent meetings to review progress. Some agencies organized special activities for gaining information about the person with dementia over time such as family member discussion meetings, ongoing reminiscing activities for people with dementia (e.g., constructing personal story books), and direct caregiver sharing meetings.

Procedure for Using the Dementia Outcomes Care Planning Tool (continued)

What to focus on: It is suggested to begin with an overview of the entire set of outcomes and indicators to work with initially for each person, then choose a few indicators that may have the most impact. By prioritizing the indicators and asking for input from the family and person with dementia on establishing these priorities, there will be the greatest chance for successes that will provide momentum to continue the process.

Supportive good practice information and models: It is important that the people providing day to day care and allocating resources understand the good practice and how it relates to the indicators being measured. The agencies that piloted this tool received a four-hour training that included good practice concepts and referred to some specific resources as examples. A list of all of the items used in the training is found on the last page of this procedure. These are not intended to be all-inclusive, but are rather examples of how to implement some of the suggestions found in the best practice section of the tool. The extent of training needed will depend on the level of current knowledge providers already have. In general, these were the areas covered for the pilots to insure everyone had a baseline of knowledge:

- A special procedure for assessing pain and implementing a pain control regimen for persons with dementia who may be unable to communicate that they are in pain.
- A procedure for observing and documenting over at least a week's time the person with dementia, environment and behavior of others when behavioral symptoms are a problem needing to be addressed.
- Review of reversible/treatable causes of dementia symptoms, and medical issues that can exacerbate symptoms in persons with Alzheimer's disease and related dementia.
- Discussion of reasons why it is so important to get a good diagnostic work up from a dementia diagnostic specialist/clinic and how and where to access these services locally.
- Comparison and contrast between the use of parenting skills and Alzheimer's caregiving skills with communication and problem solving skill review.
- A structured, engaging, empowering model of activity programming.
- An assessment and suggestions for creating a dementia friendly environment.
- A review of the effects of trauma on someone with Alzheimer's disease.
- Strategies for working with people in different stages of Alzheimer's disease.
- Discussion of types of dementia other than Alzheimer's disease and strategies for working with individuals who have them.
- **Review of the concept of person centered care, and definitions of outcomes, indicators and measures.**

- Procedure for Using the Dementia Outcomes Care Planning Tool (continued)

Care Planning and Implementing Changes: Recommendations from pilot agencies are to start small and implement changes in such a way that you can tell what is impacting the person's situation. Implementing too many things at once may lead to an inability to detect which strategies are having a positive effect and which are not. Make sure that everyone who works with the individual knows what the care plan is, how changes are being implemented and what to track to promote consistency. In situations where difficult behavior is being addressed, it may be necessary to have weekly meetings to assess progress and strategies until changes become routine. This is as much to support the staff as it is to support the person with dementia. Emphasize activities and processes that promote relationship building. It is as important to learn and share with everyone what is being done right as clearing the air on things that aren't successful. You need to do both.

Constructing the Care Plan:

1. Read through the Dementia Outcomes Care Planning Tool. Consider the issues that the person with dementia in your care may have.
2. Do an initial ranking of where the person may be on a scale of 1 to 5 for each of the indicators, then prioritize them in order of importance according to which outcomes and indicators may bring the best results if interventions are implemented.
3. Hold a team meeting to compare team perceptions and negotiate which outcomes and indicators are most relevant to work on.
4. Follow the example below on how to write the care plan.

Case Example:

Linda R. is an 86 year old widow who has lived at The Courtyard assisted living, an eight resident home, for two years. Although Linda seemed to have some problems with confusion when she first moved in, now it is becoming apparent that she has symptoms of dementia. Linda is more withdrawn lately, seems to be getting lost finding her room and has been found rummaging in other residents' drawers looking for pictures of her family. In the afternoon Linda seems upset and reports that she has to get home to make dinner for her kids and get ready for the girl-scout troop, which she led for 20 years, often at her home. Linda has been wearing the same clothes several days in a row and forgetting to wash lately too, which worries her daughters when they come to visit. Linda is often found sitting alone in her room staring out the window at the garden and nearby bird feeder when the daughters come to visit, unlike the way she was as a "social butterfly" with others when she first moved in. Linda seemed to change most six weeks ago when the activity therapist went out on maternity leave for three months. The Courtyard staff members have noticed over the last two weeks that Linda is still able to help in the kitchen when she is asked to and seems to enjoy it. The staff decide that the Dementia Outcomes Care Planning Tool may be helpful in providing ways to help Linda.

Here is what the Courtyard staff decided to include in Linda R.'s care plan.

Outcome #1

As a person with dementia, I have the best possible physical well being

Indicators:

- 1. *I am well hydrated***
- 2. I am well nourished**
- 3. I am comfortable – free from pain**
- 4. I am physically active**
- 5. I am clean**
- 6. I am safe**
- 7. My medical needs are being treated by people knowledgeable in dementia**
- 8. I receive the least restrictive intervention for my behavior symptoms**

Indicator #1: The staff did not notice any changes in Linda's eating habits, but weren't sure about her fluid intake. However, with dehydration being a risk factor for afternoon agitation, staff decided to have the nurse test Linda's skin turgor and monitor her fluid intake for one week to see if she was getting enough in the afternoons to rule out dehydration. This trial did show that dehydration was a problem. Staff then asked Linda and her daughters to give them a list of Linda's favorite things to drink, and foods (like soup and watermelon) that are high in fluids. A schedule was then implemented to encourage Linda's fluid intake throughout the day to see if it made a difference in her afternoon mood.

Indicator #7: In order to rule out any other underlying medical and mental health issues, the staff decided to encourage the daughters to have Linda get a diagnostic work up at the local dementia clinic, since Linda had never had one.

Indicator #5: Linda being clean was the daughter's biggest concern. The staff observed Linda's morning routine and discovered that she was forgetting about the clothes in her closet because the door was closed, and she was putting on the first thing she saw in the morning - her dirty dress from the day before. She had also stopped wearing clothes that she had to put on over her head because it frightened her to do so when she was alone because she felt dizzy. Linda didn't wash or comb her hair because the new aid had been tidying up her room and putting away her hairbrush and face soap where she Linda couldn't see them when she was getting ready. The staff decided to add an evening routine where Linda was prompted to choose and lay out her clothes for the next day. In the morning staff added a prompt to Linda's routine where Linda was given her hairbrush, washcloth and soap to wash and get ready.

Linda responded well to these visual cues and was able to dress in clean clothes and get washed and ready with these minimal prompts. Staff found that an added result of the changes in routine to prompt fluids and spend a few minutes with Linda in the evening and morning, Linda and her caregivers also formed a more rewarding relationship.

Procedure for Using the Dementia Outcomes Care Planning Tool (continued)

Outcome #3:

As a person with dementia, I have hope because my future is valued and supported.

Indicators:

- 1. I participate to my capacity in all decisions effecting my life**
- 2. I am useful and make contributions of value**
- 3. I plan and do things I've wanted to do while I still can**
- 4. I have the emotional support and encouragement that I need**
- 5. I have positive things to look forward to and do**
- 6. I have a legally supported plan for my future needs and wishes**
- 7. My previous wishes are honored as my capacity diminishes**
- 8. I continue practices that nourish me spiritually**

Indicator #2: Linda seemed to enjoy contributing to the household by helping to prepare meals. It seemed to remind her of the preparations she made to host the girl-scout troop she led for 20 years. The staff decided to incorporate this into Linda's routine to see if it could minimize the upset mood she seemed to get into in the late afternoons. The daughters were invited to bring Linda's memorabilia on her girl-scout days to the home and they and Linda reminisced about all of the activities they did together as girl scouts. This gave staff a wealth of information to draw from in setting up a late afternoon activity for Linda and other residents. Linda helped prepare for the activity, helped to lead the group and helped with the meal regularly, and peer relationships developed between the residents who were participating.

There is a separate attachment of sample page from Linda's care plan outlining the information from Outcomes #1 and #3.

Dementia Outcomes Care Planning Tool Good Practices Resource List

This is a list of resources that were used for training Dementia Outcomes Care Planning Tool pilot sites. They are meant to be suggestions and do not constitute an all-inclusive list of potential resources.

1. Procedures for observing and documenting behavior and environment.

- "Alzheimer's Disease Activity Focused Care". Helen, Carly. Butterworth, Heinemann, Boston, MA; 1998. Has excellent examples of forms, discussions of ways to empower staff and how meetings about observations should be held.
- "Creating Successful Dementia Care Settings". Calkins, Margaret P., Perez, Kristin, Proffitt, Mark – "Volume three – Minimizing Disruptive Behaviors" video and book (from a four volume and three video training set) by Innovative Designs in Environments for an Aging Society (IDEAS) 888-337-8808; Health Professions Press, 2001.

2. A structured, engaging, empowering model of activity programming.

- "Rekindling the Spark of Life – Joyful Activities for People with Dementia" Video and Training Manual Set. Verity, Jane, Dementia Care Australia; 1999
www.DementiaCareAustralia.com This is an excellent resource for developing a club approach to activity programming. Ms. Verity studied with Thomas Kitwood and has an actual formula of person centered approaches that bring people with dementia to life. Highly recommended along with her web site that has numerous activity products.

3. Procedure for assessing pain and implementing a pain control regimen for persons with Dementia.

- "Improving Management of Physical Pain and Affective Discomfort for People with Dementia in Long Term Care – The Assessment of Discomfort in Dementia Protocol (ADD)" Kovach, Christine PhD, RN, et al: Marquette University College of Nursing, Milwaukee, Wisconsin; 1997. Contact University of Wisconsin Center for Age and Community at 414-229-2740, www.uwm.edu/Dept/ageandcommunity/ Or Cathy Kehoe 608-267-2439 kehoe@dhfs.state.wi.us.

4. Comparison and contrast between the use of parenting skills and Alzheimer's caregiving skills with communication and problem solving skill review.

- "Changing Our Minds: From Parenting to Caregiving A Mentoring Tool for Alzheimer's Caregivers Training Manual" Kehoe, C. WI Dept of health and Family Services, Madison, Wisconsin; 2001. Available on DHFS web site at: www.dhfs.wisconsin.gov/aging/genage/alzfc.htm, or from Cathy Kehoe 608-267-2439 kehoe@dhfs.state.wi.us.

Dementia Outcomes Care Planning Tool Good Practices Resource List (Continued)

5. Strategies for working with people in different stages of Alzheimer's disease.

- "Alzheimer's Disease: Inside Looking Out". Video Terra Nova Films 800-779-8491, www.terranova.com. Good depiction of people in early stages of Alzheimer's disease.
- "Communicating with Moderately Confused Older Adults". Video Training Series
- "Communicating with Severely Confused Older Adults". Miller-Dwan Foundation; 1998. Both videos available through Terra Nova Films (1-800-779-8491). The first video covers working with people in middle stages of Alzheimer's disease and second is later stages.

5. An assessment and suggestions for creating a dementia friendly environment.

- "The Complete Guide to Alzheimer's Proofing Your Home". Warner, M., Ageless Design; 2001 (Available through the Alzheimer's Store 800-752-3238 or www.alzstore.com)
Another excellent resource, as are the ingenious adaptive aids on the web site.
- **"Planning Guide for Dementia Care at Home a Reference Tool for Care Managers"**. and accompanying "Alzheimer's Disease Home Safety Assessment." Developed by WI Department of health and family Services, Wisconsin Alzheimer's Institute and The Alzheimer's Association South Central Wisconsin Chapter, 2003. Available on DHFS web site at: www.dhfs.wisconsin.gov/aging/genage/alzfc.htm, or from Cathy Kehoe 608-267-2439 kehoe@dhfs.state.wi.us.
- **"Designing the Physical Environment for Persons with Dementia"**. Audiovisual presentation The Wesley Hall Alzheimer's Disease Project two Year Demonstration Project Chelsea United Methodist Retirement Home Chelsea, MI University of Michigan Institute of Gerontology The Regents of the University of Michigan 1987. Available through Terra Nova Films. This has good principles for developing or converting to a dementia friendly facility.

6. Review of the concept of person centered care

- "Dementia Reconsidered". Kitwood, Tom. Open University Press, Buckingham, England; 1997. Also, the work of The Bradford Dementia Group who has continued Tom Kitwood's work, and their "Well Being and Ill Being Profile" tool developed by Errolyn Bruce. Bradford University School for Health Studies, Unity Building, 25 Trinity Road Little Horton, Bradford BD5 0BB.
<http://www.brad.ac.uk/acad/health/bdg/>.

Project Description: Dementia Quality of Life Outcomes

As part of the State of Wisconsin's initiative to improve services for people with dementia in the community based long term care system, an advisory committee was formed to define quality of life outcomes important to people with dementia. From March through June 2002, the committee met for six full day working sessions. Committee members identified seven core outcomes with related indicators, measures and suggestions supporting good practice. The committee was comprised of 23 experts representing each service field of dementia care and region of the state, and included two dementia family caregivers and a consumer in the early stages of Alzheimer's disease.

The ***Dementia Quality of Life Outcomes Care Planning Tool for Providers*** is the result of the committee's work to develop a tool that would guide providers to plan ways of supporting the best quality of life possible for people suffering from Alzheimer's disease and related dementia. The future direction of the project includes dissemination and use of these outcomes as a means to collaborate and coordinate interdisciplinary care for individuals across systems and providers in Wisconsin's community based long-term care system.

Advisory Committee Members

1. **Phyllis Blackburn** Director Milwaukee Community Dementia Service Bank
St. Ann Center for Intergenerational Care Inc., Milwaukee WI.
Day services, in-home services, respite. (Southeastern region)
2. **Sue Blount** Regional Field Operations Supervisor
Southern Regional Office, WI Bureau of Quality Assurance.
Madison WI. Licensing and compliance in residential facilities.
(Southern region)
3. **Rose Boron** President Wisconsin Elder Alliance LLC, Mosinee WI.
Long term care consultant and former assisted living provider.
(Northern region)
4. **Heather Bruemmeer** Regional Long Term Care Ombudsman, Wisconsin Board on
Aging and Long Term Care, Green Bay WI.
Long term care resident advocacy. (Northeastern region)
5. **Robin Ecoff** RN Care Manager Waukesha County Department of Health
and Human Services, Waukesha WI. (Retired). County
community based care management. (Southeastern region)

- 6. Dorrae Fietz** Adult Day Services Provider
Holy Family Memorial Adult Day Services, Manitowoc WI.
(Northeast region)
- 7. Monica Froh** Quality Assurance Consultant The Management Group,
Madison WI. County care plan monitoring and review of
community based long term care services. (Statewide focus)
- 8. Nancy Holtz** Executive Director, Interfaith Volunteer Coordinator
ABC Connections, Portage WI. (Southern region)
- 9. Noreen Kuroski** Director Monroe County Senior Services
County based senior services and senior center.
Sparta WI. (Western region)
- 10. Barbara Lawrence** BSN MS Senior Outreach Specialist, University of Wisconsin
Medical School
Wisconsin Alzheimer's Institute, Madison WI. (Statewide focus)
- 11. Kim Marheine** Program Director
Alzheimer's Association of Greater Wisconsin, Neenah WI.
(Northern region)
- 12. Alice Mirk** Family Care Implementation and Technical Assistance
Manager
WI Department of Health and Family Services Office of
Strategic Finance, Center for Delivery Systems Development
(Statewide focus)
- 13. Bob Nichols** Attorney, retired. Consumer and advocate. Green Bay WI
(Northeast region)
- 14. Dennie Nichols** Family Caregiver, Corporate Guardianship Specialist
Professional Guardianships Green Bay WI (Northeast region)
- 15. Mary Pike** Family Caregiver, Volunteer & Board Member
South Central WI Alzheimer's Association, Madison WI.
(Southern Region)
- 16. Dianne Rhein** Regional Planner, Program Consultant
AgeAdvantAge Area Agency on Aging, Altoona WI.
(Western Region)

- 17. Carolyn Schuleine** Social Worker/Adult Family Home Coordinator, Community Support Program, Wood County Unified Services Marshfield WI. Recruiting and support of small home-style care providers. (Northern region)
- 18. Kathy Vite-Hazelton** CSW, Social Worker - CCO
Aging and Disability Resource Center of Kenosha County
Kenosha WI. (Southeastern region)
- 19. Patrick Vohen** RN, Alzheimer's Community Resources Committee Vice Chair, Director of Community Based Residential Facilities & Assisted Living Services, Beaver Dam Community Hospital
Remembrance Home, Beaver Dam WI. (Southern region)
- 20. Donna McDowell** Director, Wisconsin Bureau of Aging and Long Term Care Resources, Madison WI. (Statewide focus)
- 21. Cathy Kehoe** Alzheimer's Service Developer, Wisconsin Bureau of Aging and Long Term Care Resources, Madison WI. (Statewide focus)
- 22. Lora Warner** Ph.D. Consultant for Project. President, Planning and Evaluation Associates; Professor University of WI Green Bay.

Questions and comments about this project or the use of the ***Dementia Quality of Life Outcomes Care Planning Tool for Providers*** may be directed to:

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WI Department of Health and Family Services
1 West Wilson Street, PO Box 7851
Madison, WI 53707-7851
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Please see the Wisconsin Department of Health and Family Services web site for additional information, materials and resources on dementia care:
<http://dhfs.wisconsin.gov/aging/genage/alzfcgsp.htm>

Person's Name Linda R.

Outcome # 1 Title: Best Physical Well-Being

Assessment/Review Dates: A 1/1/04 B 3/1/04 C 6/1/04 D /1/04

Quality Indicator	Assessment of Indicator Satisfaction	Good Practice Plan and Measures	Review and Changes
# 1 Hydration	Person is Well Hydrated 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)	(A) Plan - Prompt Linda with a variety of preferred fluids every 3 hours between 8 am and 6 pm Measures - Observe Linda drink fluids	(B) Revise plan to prompting every 2 hours (C) Continue (D) Continue
# 7 Treated by dementia specialist	Person is treated by dementia specialist 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)	(A) Plan – Rule out depression, medical causes for agitation Measures – Results of assessments. (B) Plan – Trial of Aricept to see effects on afternoon withdrawn and agitated behavior. Measures – Observation and rating of mood between 2:00PM and 5:00 PM daily. (C) Continue (D) Continue	(A) Assessments show no depression, medical causes, but declines in cognitive scores. (B) Observe for changes with medication trial – rank 1-3 on levels of agitation and of withdrawal from others. (C) Some improvement, dose increased. (D) More improvement – especially when activities added from 3:00 PM – 4:PM
# 3 I am Clean	Person is clean 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)	Plan – - Linda will choose and lay out clothes before bedtime each day with prompts from staff. - Linda will wash up and brush hair in morning when she sees soap, brush and washcloth. Measures: Observation by staff.	(A) Linda does well will visual and sometimes verbal prompts. Enjoys interacting with staff as part of routine. Wears clean clothes and washes up daily. (B) Continue. (C) Continue. (D) Continue.

Signatures _____

Person's Name Linda R.

Outcome # 3 Title: Hope Because My Future is Valued, Supported

Assessment/Review Dates: A 1 / 1 / 04 B 3 / 1 / 04 C 6 / 1 / 04 D / 1 / 04

Quality Indicator	Assessment of Indicator Satisfaction	Good Practice Plan and Measures	Review and Changes
# 2 Useful and makes contributions	Person is Useful, making contributions 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)	(A) Plan – Linda will be invited help staff prepare evening meal and do so as desired. Measures – Number of times invitation accepted and Linda helps. (B) Linda will assist staff in leading a girl scout troop meeting two times per week as desired between approximately 3-4 PM. Measures – Number of times Linda accepts and helps with group.	(A) Linda responds well, and seems to enjoy activity, still seems bored in late afternoon. (B) Modify plan to add additional activity two times per week – loved girl scout meeting activity tried with daughters. (C) Linda responding well. Continue. (D) Continue.
#	Person is 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)		
#	Person is 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)		

Signatures _____

Person's Name _____

Outcome # _____ Title: _____

Assessment/Review Dates: A ____ / ____ / ____ B ____ / ____ / ____ C ____ / ____ / ____ D ____ / ____ / ____

Quality <i>Indicator</i>	Assessment/Quality Review of Indicator Satisfaction	Good Practice Plan and Measures	Review and Changes
#	Person is 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)		
#	Person is 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)		
#	Person is 1 2 3 4 5 (A) 1 2 3 4 5 (B) 1 2 3 4 5 (C) 1 2 3 4 5 (D)		

Signatures _____